Measuring health-related quality of life in adults with chronic conditions in primary care settings

Critical review of concepts and 3 tools

Carri Hand PhD

Abstract

Objective To describe health-related quality of life (HRQOL) conceptual frameworks, critically review 3 commonly used HRQOL scales relevant to adults with chronic conditions in primary care settings, and make recommendations for using HRQOL scales in primary care practice.

Data sources Information was accessed regarding HRQOL conceptual and theoretical approaches. A comprehensive search strategy identified 3 commonly used scales that met the review criteria and evidence regarding use of the scales in adults with chronic conditions in community settings.

Scale selection Scales were selected if they were designed for clinical use; were easy to administer; were generic and broad in content areas; and contained some individualized items. Scales were critiqued according to content development, theoretical basis, psychometric properties, scoring, feasibility, the concepts being measured, and the number of items that measured an individualized concept.

Synthesis Early HRQOL approaches focused on health and functional status while recent approaches incorporate individualized concepts such as the person's own values and the environment. The abbreviated World Health Organization Quality of Life Scale (WHOQOL-BREF), the 36-Item Short Form Health Survey (SF-36), and the Duke Health Profile were critiqued. All address physical, mental, and social domains, while the WHOQOL-BREF also addresses environment. Psychometric evidence supports use of the SF-36 and WHOQOL-BREF with this population. The SF-36 has the most evidence of responsiveness but has some floor and ceiling effects, while the WHOQOL-BREF does not appear to have floor or ceiling effects but has limited evidence of responsiveness. The WHOQOL-BREF has the highest proportion of individualized items.

Conclusion Measurement of HRQOL in adults with chronic conditions can support patient management and contribute to primary care service evaluation. Scales that are based on a broad definition of health and that address the individualized nature of HRQOL are appropriate for these purposes, such as the WHOQOL-BREF. Psychometric evidence supports using this scale for adults with chronic conditions; more information about its responsiveness is needed.

EDITOR'S KEY POINTS

- Measurement of health-related quality of life in adults with chronic conditions in primary care settings can support patient management and intervention and contribute to service evaluation.
- Scales that are based on a broad definition of health and well-being and that include individualized items, as the abbreviated World Health Organization Quality of Life Scale does, are appropriate for these purposes.
- Evidence related to psychometric properties supports the use of the abbreviated World Health Organization Quality of Life Scale for adults with chronic conditions, although more information about its responsiveness is needed.

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Mesurer la qualité de vie liée à la santé des adultes souffrant de problèmes chroniques en milieux de soins primaires

Révision critique des concepts et de 3 outils

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Résumé

Objectif Décrire les cadres conceptuels de la qualité de vie liée à la santé (QDVLS); effectuer une révision critique de 3 échelles de la QDVLS couramment utilisées et pertinentes pour les adultes souffrant de problèmes chroniques dans des milieux de soins primaires; et présenter de recommandations concernant l'utilisation d'échelles de la QDVLS dans la pratique des soins primaires.

Sources des données Nous avons accédé à des renseignements concernant les approches conceptuelles et théoriques relatives à la QDVLS. Une stratégie de recherche exhaustive a permis de cerner 3 échelles communément utilisées qui répondaient aux critères de la révision, de même que des données probantes à propos de l'utilisation de ces échelles dans le cas d'adultes souffrant de problèmes chroniques en milieu communautaire.

Sélection des échelles Les échelles étaient retenues si elles étaient conçues à des fins cliniques; étaient faciles à administrer; étaient génériques et portaient sur un contenu élargi; et comptaient certains éléments individualisés. Les échelles ont fait l'objet d'une critique en fonction de l'élaboration du contenu, du fondement théorique, des propriétés psychométriques, de la notation, de la faisabilité, des concepts mesurés et du nombre d'éléments mesurant un concept individualisé.

Synthèse Les premières approches de la QDVLS se concentraient sur la santé et l'état fonctionnel, alors que les approches plus récentes intègrent des concepts individualisés, comme les valeurs particulières à la personne et son environnement. L'Échelle abrégée de la qualité de vie de l'Organisation mondiale de la Santé (WHOQOL-BREF), le SF-36 (formulaire de sondage court sur la santé en 36 éléments) et le Duke Health Profile ont fait l'objet d'une évaluation critique. Tous se penchent sur les domaines physiques, mentaux et sociaux, mais le WHOQOL-BREF s'intéresse aussi à l'environnement. Des données scientifiques en psychométrie appuient l'utilisation du SF 36 et du WHOQOL-BREF avec cette population. La réceptivité du SF 36 est corroborée par plus de données probantes, mais il comporte certains effets de plancher et de plafond, tandis que le WHOQOL-BREF ne semble pas avoir d'effets de plancher et de plafond, mais sa réceptivité n'est appuyée que par des données limitées. Le WHOQOL-BREF compte la proportion la plus élevée d'éléments individualisés.

Conclusion La mesure de la QDVLS chez les adultes souffrant de problèmes chroniques peut appuyer la prise en charge des patients et contribuer à l'évaluation des services de soins primaires. Les échelles qui se fondent sur une définition large de la santé et s'intéressent à la nature individualisée de la QDVLS sont appropriées à ces fins, comme le fait le WHOQOL-BREF. Des données probantes en psychométrie appuient l'utilisation de cette échelle avec des adultes souffrant de problèmes chroniques; il faudrait plus de renseignements concernant sa réceptivité.

POINTS DE REPÈRE DU RÉDACTEUR

- La mesure de la qualité de vie liée à la santé des adultes souffrant de problèmes chroniques en milieux de soins primaires peut appuyer la prise en charge du patient et les interventions indiquées et contribuer à l'évaluation des services.
- Les échelles qui se fondent sur une définition large de la santé et du bien-être et qui incluent des éléments individualisés, comme le fait l'Échelle abrégée de la qualité de vie de l'Organisation mondiale de la Santé, sont appropriées à ces fins.
- Des données probantes concernant les propriétés psychométriques de l'Échelle abrégée de la qualité de vie de l'Organisation mondiale de la Santé appuient son utilisation pour des adultes souffrant de problèmes chroniques, mais il faudrait plus de renseignements concernant sa réceptivité.

Cet article a fait l'objet d'une révision par des pairs.
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As primary care transforms across Canada, greater emphasis is being placed on quality of care and accountability for outcomes, as well as on prevention and management of chronic conditions and patient self-management.[1] Typical indicators of patient outcomes (such as blood pressure or smoking rate) do not capture the breadth of services that are being provided in primary care, nor do they provide enough detail to guide quality improvement. Health-related quality of life (HRQOL) is a concept that can be useful in evaluation and improvement efforts. This paper will provide guidance to primary care providers regarding the use of HRQOL instruments in practice for adults with chronic conditions.

Health-related quality of life is defined as those aspects of quality of life (QOL) that directly or indirectly relate to health.[2,3] While the terms *quality of life* and *health-related quality of life* are often used interchangeably, the 2 are generally considered distinct concepts. Quality of life can be considered overall satisfaction with life, either as a single concept[4] or broken down into domains.[5] Health-related quality of life is a narrower concept that includes physical, psychological, and social domains[6,7] and can be considered one's subjective assessment of the physical, psychological, and social domains of health.[7] Health-related quality of life scales can measure the results of health care, supplementing traditional physiologic measures of health status.[8]

Health-related quality of life scales might be specific, applying to certain conditions, populations, or functional issues, or they might be generic. Generic scales are preferred when measuring HRQOL in people with comorbidities[9] or when evaluating multicomponent interventions. They have similar or better responsiveness to change compared with disease-specific scales.[10-13] Generic scales include health profiles, which generate scores in a number of different domains, and health utility measures, which generate a single score of HRQOL such as a quality-adjusted life-year.[6] Although the reliability of patient-reported outcomes such as HRQOL might be challenged, most common clinical tools have similar levels of error to patient-reported outcome measures.[14] Adults with chronic conditions such as arthritis, chronic obstructive pulmonary disease (COPD), congestive heart failure, diabetes, hypertension, and heart disease experience lower HRQOL than people without these conditions do[15-18]; the presence of comorbidity further decreases HRQOL.[19-22] Presence of chronic conditions relates to a number of HRQOL domains such as increased pain[23] and difficulties in physical function,[9,24] mental health,[25] general health, social function,[26] home management,[27] energy, and sleep.[28] All of these domains can be affected by primary care services (eg, pain medication, mental health counseling, and self-management education to assist in managing daily activities). Measuring HRQOL can be an important component of evaluating primary care services, including complex processes such as intervention dose-response relationships.[29]

In addition to evaluating service outcomes, measuring HRQOL in adults with chronic conditions can promote high-quality patient care. Health-related quality of life scales capture the patient's perspective, a key aspect of providing the patient-centred, collaborative care that is important to patients[30,31]; this type of care can also create positive outcomes for patients such as improved self-management skills.[32] Measuring HRQOL can improve clinician awareness of patient concerns and patient-clinician communication,[33,34] supporting service and program planning. Measuring HRQOL can also improve patient HRQOL itself.[35]

To appropriately select and use HRQOL scales, it is important to understand the conceptual basis, concepts measured, and psychometric properties of HRQOL scales. While most HRQOL scales cover mental, physical, and social domains, the scales' items might address different concepts. For example, one scale might ask about difficulty sleeping, while another might ask about satisfaction with sleep. The latter concept is more "subjective" or individualized and related to the person's own life.[36] Previous reviews of HRQOL scales have described the psychometric properties and domains of the scales[37] or the conceptual model underpinning each scale.[38] No previous review has closely examined the concepts being measured or use of HRQOL scales for adults with a range of chronic conditions in primary care settings. To fill these gaps and assist primary care practitioners in using HRQOL scales, the objectives of this paper are to describe approaches to conceptualizing HRQOL, critically review 3 commonly used HRQOL scales relevant to adults with chronic conditions in primary care settings, and make recommendations for using HRQOL scales in primary care practice.

DATA SOURCES

Several steps were performed to gather and synthesize information.

Theoretical approaches

Approaches to HRQOL were synthesized by accessing theoretical papers about HRQOL.

Scale identification

Generic, profile-type HRQOL scales commonly used for adults were identified by searching MEDLINE and EMBASE. Search terms included the MEDLINE subject headings *health status indicators* or *questionnaires* or *outcome assessment (health care)* and *quality of life* or *health status*, as well as the EMBASE subject headings *health survey* or *questionnaire* or *outcome assessment* and *quality of life* or *health status*. Only English-language scales

for those aged 18 years and older published from 1980 to 2014 were included. Given the numerous studies on QOL, health status, and HRQOL, the search was also limited to review articles, as such articles would likely capture the most commonly used scales. The search identified 1553 articles, 36 of which reviewed QOL, health status, or HRQOL scales. From these 36 articles, 26 QOL, HRQOL, or health status scales were identified. One of the reviews identified the most commonly evaluated patient-reported health outcome measures up to the year 2000.[39] The HRQOL profile-type scales that were identified included the Dartmouth COOP Functional Assessment Charts, the Duke Health Profile, the Health Assessment Questionnaire, the Nottingham Health Profile (NHP), the 12-Item Short Form Health Survey (SF-12), the 36-Item Short Form Health Survey (SF-36), the Sickness Impact Profile, and the World Health Organization Quality of Life Scale (WHOQOL-100).[39] Another review identified the most commonly used generic HRQOL instruments from 2000 to 2006 and the profile-type scales were the Dartmouth COOP Functional Assessment Charts, the NHP, the SF-36, the Sickness Impact Profile, and the WHOQOL-100.[40] All of the instruments identified in the 2 reviews were also identified in the current search, while the current search also identified the abbreviated WHOQOL-100 (WHOQOL-BREF). The remaining instruments identified by the current search either focused on QOL broadly rather than HRQOL, or focused on a specific population such as older adults.

SCALE SELECTION

Three HRQOL scales were selected to be critically appraised based on the following criteria:

- they were designed for clinical use;
- they were short and easy to administer and score;
- they were generic and applicable to primary care patients with varying diagnoses;
- they had broad content areas (ie, physical, psychological, and social domains); and
- they contained some individualized items.

These criteria were applied to the 9 potential scales identified above. The Dartmouth COOP Functional Assessment Charts, the Duke Health Profile, the NHP, the SF-12, the SF-36, and the WHOQOL-BREF all met the selection criteria. The SF-12 and Dartmouth COOP Functional Assessment Charts are both based on the SF-36,[41] and as the SF-36 was the more frequently used tool,[39] it was selected for review. Finally, the NHP is slightly longer than the remaining 3 instruments (45 items)[42]; therefore, it was not selected for review.

Scale descriptions and properties

Information was gathered regarding the development, content, and psychometric properties of the selected scales when used for adults with chronic conditions from textbooks and user manuals, and by searching MEDLINE and EMBASE. Search terms included key words for the scale names and abbreviations, psychometric properties, and diagnosis (eg, heart, cardiac, diabetes, COPD, arthritis). Arthritis, cardiac conditions, diabetes, and COPD are the most prevalent chronic conditions in older adults[43] that also affect QOL[44]; thus, evidence related to these diagnoses was identified. The search was limited to English-language articles published from 1980 to 2014. To better apply to a Canadian primary care context, only evidence from Western countries regarding community settings was reported.

Critical review

The selected scales were critically reviewed according to established criteria: content development, theoretical basis, psychometric properties, scoring, and feasibility.[45,46] The scales were further assessed regarding the concept being measured in each item and the number of items that measure an individualized concept such as satisfaction with ability, distress, enjoyment, domain importance or goals, or comparison to the person's own standards.[36]

SYNTHESIS

Approaches to HRQOL

Functional and health status approaches to HRQOL. Most HRQOL approaches focus on function, health status, or symptoms, and locate the cause of difficulties within the person, with little attention to the person's environment. These approaches are based on a definition of health as physical, mental, and social well-being[47] and involve physical, mental, social, and role domains.[48] In functional status approaches, no conceptual models were developed and the focus was on assessing function to make inferences about QOL. In health status approaches, QOL was conceptualized as closely related to health but details of this relationship were not specified.[49] Most approaches did not consider the person's subjective judgments about QOL concepts and sometimes relied on an outside observer to measure QOL.[49] The NHP,[50] the SF-36,[51] and the Duke Health Profile[52] are examples of scales that use the functional and health status approaches to HRQOL.

Alternative approaches to HRQOL. Alternative approaches to HRQOL move beyond health status to incorporate concepts such as participation in society, satisfaction with aspects of life,[53] and the environment. They emphasize individualized concepts such as goals, expectations, satisfaction, distress, and enjoyment,[49,54,55] which

are critical within appraisal of HRQOL[36,56] and help health practitioners gain a better understanding of patients' needs and desires. Recent models have also incorporated the International Classification of Functioning, Disability and Health[57] or the social model of disability into HRQOL, locating the source of difficulties in the person and the environment. Such approaches encourage environmental interventions or adaptations and might assign smaller importance to impairments, as particular limitations do not necessarily affect HRQOL negatively.[58]

The World Health Organization (WHO) defines QOL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[55] They developed a model of QOL based on this definition that includes physical health, psychological state, independence, social relationships, and environment. It includes more objective concepts such as perceived function but also addresses the meaning or importance of functional levels.[55] A measure grounded in this approach is the WHOQOL-BREF.[59] Although the WHO model of QOL purports to describe overall QOL, it actually appears to describe HRQOL; part of the rationale for developing the WHOQOL-100 was to address a gap in health measurement, in that previous scales focused on the effect of disease on function and perceived health in a mechanistic way.[55]

Critical reviews

The WHOQOL-BREF,[59] the SF-36,[51] and the Duke Health Profile[52] were identified as commonly used[37,38,60-63] generic HRQOL scales among adults and older adults with chronic conditions that met the review criteria. The WHOQOL-BREF is intended to evaluate QOL and the effect of a disease, disorder, or health intervention on QOL, across conditions and disorders and nations in medical practice and research.[55] The health care focus differentiates the WHOQOL-BREF from other measures of QOL that might be too broad for use in health care settings. It was developed through a multistage international process and extensive field testing with people who had varying diagnoses and with a small percentage of healthy individuals. It is based on the WHO definition of QOL.[59]

The SF-36 is intended to evaluate health status in clinical practice and research, across conditions and with healthy people. The content was based on previous questionnaires and a definition of health status as involving physical, mental, social, and role domains.[51]

The Duke Health Profile is intended to measure functional health status in adults in primary care practice and research.[52] The content was based on previous scales and the literature[64] and has a definition of health that involves physical, mental, and social well-being, the ability to perform social roles, and coping.[65] **Table 1** provides the full critique of each scale.[16,18,45,59,64,66-98]

DISCUSSION

The WHO approach to HRQOL builds on the functional and health status approaches and includes physical, social, and psychological domains and interaction with the environment. It contains ideas of health and well-being and individualized concepts such as goals, expectations, satisfaction, and importance. This type of approach is crucial to providing patient-centred care that takes into account the context of patients' lives.

The 3 reviewed scales have several similarities and differences. All address physical, mental, and social domains, while the WHOQOL-BREF also addresses environmental areas (ie, living conditions, access to health services, transportation, leisure opportunities, finances, information, safety, and physical surroundings). The development process and conceptual framework of the WHOQOL-BREF are stronger than those for the SF-36 and the Duke Health Profile. There is a variety of evidence related to the psychometric properties of the scales, and generally there are fewer published studies regarding the Duke Health Profile. The SF-36 has some evidence of responsiveness but might suffer from floor and ceiling effects, while the WHOQOL-BREF does not appear to have floor or ceiling effects but only 1 study of its responsiveness was identified. The WHOQOL-BREF has the highest proportion of items that are individualized.

Selection of HRQOL scales requires judgment on the part of the user.[99] Health-related quality of life measurement can be useful in clinical practice for assessment and intervention planning, monitoring progress, and measuring outcomes.[100] Despite some of its limitations, the WHOQOL-BREF scale might be the best tool to use for adults with chronic conditions in primary care settings for all 3 of these purposes. It addresses patient concerns and its broad content areas can enable measurement of the outcomes of various medical and health promotion and prevention interventions. Further research is needed to assess its ability to detect meaningful change over time in patients with chronic conditions. Alternatively, the SF-36's strong focus on health and evidence of responsiveness make it particularly useful in evaluating outcomes of interventions that are aimed at improving health status. The Duke Health Profile is less useful for adults with chronic conditions owing to limited evidence regarding psychometric properties and the small proportion of individualized items.

Overall, further research is needed regarding the responsiveness and other psychometric properties of HRQOL scales in various chronic condition populations, as well as regarding how HRQOL scales can be integrated into primary care practice.

Table 1. Critique of health-related quality of life scales: *Comments regarding psychometric properties related to individuals with arthritis, cardiac conditions, chronic obstructive pulmonary disease, or diabetes.*

CHARACTERISTIC	WHOQOL-BREF	SF-36	DUKE HEALTH PROFILE
Description	26 items 4 domain scores	36 items 8 subscale scores and 2 component scores	17 items 10 domain scores
Domains	Physical, psychological, social, and environmental	Physical function, mental health, social function, role physical, role emotional, pain, vitality, general health	Physical, mental, and social health; general and perceived health; self-esteem, anxiety, depression, pain, and disability
Concepts measured (scale item numbers)	• Assessment of overall QOL, meaning in life, and life enjoyment (1, 5, and 6)* • Satisfaction in 11 areas (health, sleep, ADL abilities, work ability, self, relationships, sex life, social support, living conditions, access to health services, and transportation (2 and 16-25)* • Frequency of negative emotions (26)* • Extent to which pain prevents you from doing what you need to do (3)* • Adequacy of energy (10)* • Acceptance of appearance (11)* • Enough money to meet needs (12)* • Availability of the information needed (13)* • Need for medical treatment to function (4) • Safety of environment (8) • Ability in 2 areas (concentration and getting around) (7 and 15) • Health of the physical environment (9) • Opportunity for leisure activities (14)	• Assessment of health (1, 2, and 11a-d)* • Frequency of 5 emotions (9b-d, 9f, and 9h)* • Frequency of 4 energy states (9a, 9e, 9g, and 9i) • Accomplished less than would like (4b and 5b)* • Extent of health problems interfering with usual activities (6)* • Extent of pain interfering with usual work or housework (8)* • Frequency of health problems interfering with social activities (10)* • Limitation in 10 physical activities (3a-j) • Decrease in time spent on activities (4a and 5a) • Limited in type of activities (4c) • Difficulty in activities (4d) • Worked less carefully (5c) • Amount of pain (7)	• Likes self (1)* • Assessment of health (3)* • Happy with family relationships (6)* • Extent of negative emotions (13 and 14)* • Personal characteristics (easy to get along with, gives up too easily, comfortable around people) (2, 4, and 7) • Frequency of socializing, attending social events, and staying at home (15-17) • Difficulty in 6 areas (concentrating, climbing stairs, running, sleeping, pain, and tiring) (5 and 8-12)
Individualization	20/26 (77%) individualized items	16/36 (44%) individualized items	5/17 (29%) individualized items
Construct validity	In adults with chronic conditions: evidence of factor structure of scale,[59,66,67] convergent validity,[18,67,68] and discriminative validity[59,66,69,70]	In adults with chronic conditions: conflicting evidence regarding factor structure of scale,[71-73] evidence of convergent validity,[68,74-78] discriminative validity,[16,72-76,78-84] and predictive validity[85]	No studies of adults with chronic conditions identified. Among primary care patients: evidence of discriminative validity,[86,87] convergent validity,[64,86,87] and predictive validity[88]
Test-retest reliability (Pearson, Spearman, or intraclass correlation coefficient)	In adults with chronic conditions: >0.66 on all subscales[59,67]	In adults with chronic conditions: >0.6 on all subscales[89]; other studies found lower reliability for mental health and social function (0.52 to 0.55),[75] social function, role emotional, and bodily pain (0.53 to 0.59),[90] and social function, role emotional, and role physical (0.26 to 0.59)[76]	No studies of adults with chronic conditions identified. In primary care patients: >0.6 for all subscales except social health, perceived health, pain, and disability (0.30 to 0.59),[86] and physical health, perceived health, pain, and disability (0.41 to 0.59)[87]
Responsiveness	Some evidence of responsiveness in physical and social domains for adults with rheumatoid arthritis[67]	In adults with chronic conditions: some evidence of responsiveness for most subscales[74-76,78,82,90-96]	Some evidence of responsiveness in most subscales in cardiac rehabilitation patients[97]

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Table 1 *continued from page e380*

CHARACTERISTIC	WHOQOL-BREF	SF-36	DUKE HEALTH PROFILE
Floor or ceiling effects (> 15% scoring maximum or minimum)[45]	In adults with chronic conditions: no floor or ceiling effects noted[67-69]	Ceiling effects noted for social function,[68,71,73,75,76,81,82,98] role emotional,[68,71,73,75,76,82,92,98] role physical,[68,71,73,75,76] and bodily pain.[81] Floor effects noted for role emotional and role physical,[68,71,73,75,76,82,92,98] and physical function[76,82]	No studies of adults with chronic conditions identified. In primary care patients: ceiling effects noted for perceived health, pain, disability, and self-esteem subscales; floor effect noted for pain subscale[45]
Scoring	Straightforward	Complex scoring using computer software	Straightforward
Feasibility	Brief and easy to understand	Brief and easy to understand	Brief and easy to understand

ADL—activities of daily living, QOL—quality of life, SF-36—36-Item Short Form Health Survey, WHOQOL-BREF—abbreviated World Health Organization Quality of Life Scale.
*Indicates individualized items.

Limitations

This study might be limited by the fact that only 3 HRQOL scales were reviewed; other scales might also be useful.

Conclusion

Measurement of HRQOL in adults with chronic conditions in primary care settings can support patient management and intervention and contribute to service evaluation. Scales that are based on a broad definition of health and well-being and that include individualized items are appropriate for these purposes, such as the WHOQOL-BREF. Evidence related to psychometric properties supports the use of this scale for adults with chronic conditions, although more information about responsiveness is needed.

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Competing interests
None declared

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